

Skills such as putting on socks

## **EDUCATION COMMITTEE**

Public Hearing on H.B. 5447

An Act Concerning the recommendations of the Auditors of Public Accounts Concerning Private Providers of Special Education

Wednesday, March 14, 11:00am Room 1D of the Legislative Office Building

## Submitted by Karen Neag, Mother of a Young Adult diagnosed with Autism and Phelan McDermid Syndrome

Good Morning Senators Slossberg, Senator Boucher, Representative Fleischmann and distinguished members of the Education Committee.

I am Karen Neag and I here to talk about the difference an Out –of-District education has made with our daughter, Stephanie Neag.

Phelan McDermott Syndrome is a genetic condition which is rare, newly labeled and appears to look like autism. It's not easy for a parent to see a good future when a child has a disability as serve as our Stephanie's. When our daughter left the Birth-to-Three program; a program designed to let the public school system know the needs of a future student, she was outplaced at three years of age. Our family was told in 2000, that our town did not have trained professionals, ideal learning environments and teaching tools such as communication systems available.

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KAREN NEAG- Wednesday March 14, 2018

I have been on the board of a parent's group for twelve years called LACASA, Litchfield County Autism Spectrum Association. I have heard from many parents that since 2000 our district has not developed a program to be appropriate in educating our children with such needs as my daughter.

I have also volunteered my time with the State Board of Education to help publish in 2005, "Guidelines for Identication

and Education of Children and Youth with Autism". (Guidelines have been revised 20011.) http://portal.ctgov/-/media/SDE

These guidelines were developed by many professionals with different educational functions within Connecticut stating to be what best practice is for our disabled children. This book helps to set a standard. I can share that in development of the, "Best Practice for Teaching Children", many guidelines from other states within United States were compared. The task force in designing the guidelines for Connecticut worked hard to have similar goals as other states and was designed to have education take place within the disabled child's district.

If I may quote a summary to the guidelines: "Given that the overall goal of public education is to prepare students for the role as productive members of their community and society in general, it is important those students with autism receive instruction in environments where they can master and generalize skills to help them be prepared for life."

What happens when a student cannot gain a life's education within the town's borders? I had to place my daughter on a

school bus at three years of age and send her to a specialized program.

My photo of my daughter, shown here, I have documented the skill that I found to be my first hope of my daughters wellbeing. Seeing her put her own socks on is not something little in my eye!

If not for the hard work of many skilled teachers, aides, bus drivers of Oak Hill my daughter putting socks on amongst other taught daily living skills and academics, Stephanie's future wouldn't be as promising as it is now.

I am asking this committee to understand the challenges that families face with raising disabled children and please stop the cutting of funds to private schools and talented people who serve our children so well within Connecticut. I am truly thankful for the efforts of Oak Hills with our disabled citizens.

Thank you for hearing of our education journey,
Karen Neag